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13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information) In this study, a retrospective, descriptive design was employed to examine the relationship between perception of risk and surveillance activities (mammography and clinical breast examination) of women with a family history of breast cancer. The Revised Susceptibility, Benefits, and Barriers Scale for Mammography Screening, the CES-D, and a demographic form were administered to a convenience sample of 56 women. There were no significant findings between perceived risk and screening, nor between age or depressive symptoms with perceived risk or screening behaviors. Women with post-secondary qualifications were found to be more likely to obtain regular mammograms ($\chi^2 = 7.423$, $df = 1$, $p = 0.006$). The level of depressive symptomology was high with 34.5% of participants scoring ≥ 16 on the CES-D. A substantial portion of participants reported depressive symptoms at a level associated with clinically significant levels of depression. Women over age 50 reported significantly more depressive symptoms ($t = 2.279$, $p = .027$). Overall perceived risk was not found to have an association with screening, however depression should be considered more closely when dealing with women with higher-than-average risk of breast cancer.				
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Introduction

Women with a strong family history of breast cancer are considered to be at increased risk (Claus et al, 1990) and may gain greater benefit from regular mammograms and clinical breast examinations (CBE) than average risk women. A problem beyond the increased risk is that first degree female relatives of breast cancer patients may manifest intrusive thoughts, sleep disturbances, or stress related impairments in performance of daily activities (Lerman & Croyle, 1996). The purpose of this study was to examine the relationship between risk perception, screening practices, depressive symptoms, and demographic characteristics of women with a family history of breast cancer to gain an understanding of the influence of risk perception on health behaviors and how counseling can be tailored to meet the needs of these women.

Task 1. Subject Recruitment and Data Collection

Although funding started in July 2003, ethical approval was not obtained until January 2004. While this delayed subject recruitment, other tasks related to the thesis were completed in this time period. In February 2004, the Hereditary Breast Cancer Clinic genetic counselor sent 150 letters of invitation to participate in this study. 61 clients contacted the researcher requesting a survey. Of the 61 participants who contacted the researcher, one client declined participation because she did not meet the study criteria and one client requested a survey after the data collection period was over. Of the 59 surveys that were sent, 56 (95%) were returned completed and entered into the statistical program SPSS.

Task 2. Data Analysis

Final statistical analysis of data obtained from mail-out surveys was performed after consultation with thesis advisor. The three research questions were addressed as follows:

Question One

Is there a relationship between risk perception and screening practices for women who have a family history of breast cancer?

For this question, data were used from the susceptibility sub-scale of women who report a high perceived risk and those who reported moderate perceived risk of breast cancer. Data was recoded to identify regular screening: regular mammography is defined as reporting of at least one mammogram in the past three years if under the age of 50 and at least three mammograms in the past three years for those age 50 or older. Regular CBE is defined as reporting of at least three CBEs in the past three years.

Bivariate analyses were performed using chi-square tests to explore differences of risk with screening variables. Cross-tabulation was done to show the relationship between categories. No significant difference was found in CBE by perceived risk ($\chi^2 = 2.204$, $df = 1$, $p = 0.138$) nor mammography utilization by perceived risk ($\chi^2 = 0.850$, $df = 1$, $p = 0.356$). Of the women in this study reporting regular mammograms, there were fewer who perceived their risk to be high compared to those who perceived a moderate risk.

Question Two

Is there a difference in perceived risk, depressive symptoms, and screening practices for women with one or two relatives and those with three or more relatives who have been diagnosed with breast cancer?

For the second question, differences were examined through chi-square tests. No

differences were found in the level of perceived risk for family members ($\chi^2 = 0.094$, $df = 1$, $p = 0.759$) by the number of relatives with breast cancer.

Using the same two categories of relatives, as mentioned above, screening practices were considered. A greater percentage of women with three or more relatives with breast cancer regularly received mammograms and CBEs compared to women with fewer relatives who have breast cancer. However, in the case of mammography, the difference was not significant ($\chi^2 = 1.624$, $df = 1$, $p = 0.203$). A difference did appear for CBE ($\chi^2 = 7.381$, $df = 1$, $p = 0.007$), suggesting CBE is more likely to be done when a woman has a greater number of relatives with breast cancer.

When looking at depressive symptoms and the number of relatives with breast cancer, chi-square testing showed no significant difference ($\chi^2 = 0.007$, $df = 1$, $p = 0.933$).

Question Three

Do age, education level, or depressive symptoms relate to screening practices or to perceived risk?

The third, and final question has two parts: screening practices and perceived risk. Each of these variables are considered in relation to age, education, and depression using chi-square analysis.

The participant's ages ranged from 23-71. Population based mammography screening targets women age 50 and older. Therefore, two age categories were formed: less than and equal to 49 and greater than and equal to 50. No significant differences were found in screening practices by age. While there was a high rate of reported screening activities overall, the participants over 50 years of age were more likely to be practicing regular mammography. The 2-sample arcsine approximation power calculation for mammography by age was only 0.1656. The power of the hypothesis is weak and a much larger sample size would be needed to reduce the probability of a type II error.

Education was divided into three categories: grade 11 or less, completed high school, and completed college or university. The grade 11 or less category consisted of 4 participants in total and was combined with the completed high school category to form two groups on the basis of post-secondary qualifications. As shown in Table 16, no significant difference was found in CBE by education, however, a difference was noted in use of regular mammograms by education ($\chi^2 = 7.423$, $df = 1$, $p = 0.006$).

Chi-square testing was used to test for differences in regular mammography screening or CBE by CES-D scores. No significant differences were found between these two variables. Although screening is generally high, there appears to be a trend toward less CBE with less depressive symptomology (< 16).

Cross-tabulation and the chi-square testing were used to test for differences in perceived risk by age. No significant difference was found ($\chi^2 = 0.065$, $df = 2$, $p = 0.968$). The level of perceived risk is very similar across each group.

When examining perceived risk by education level, no significant differences were found ($\chi^2 = 0.83$, $df = 1$, $p = 0.773$). As with age, very similar numbers were observed for both education levels between moderate and high perceived risk.

There was no significant difference in perceived risk level by depressive symptoms ($\chi^2 = 1.266$, $df = 1$, $p = 0.260$). However, there was a trend toward a higher score on the CES-D with the higher level of perceived risk.

Study Limitations

The study had both strengths and limitations. The major and most obvious limitation of this study related to sample size. Less than optimal sampling has the risk of erroneous or inconclusive results and lacks representation of the target population (Polit & Hungler, 1999). Had a second letter of invitation been sent to the entire eligible population, perhaps a greater response rate would have been realized. In the end, only 43 percent of eligible participants responded to the invitation to participate.

This is a descriptive level study with a convenience sample. Women with negative associations with breast cancer may not have been willing to participate in any research which reminded them of their risk level. Their screening practices may be excessive or non-existent due to anxiety, depressive symptoms or other reasons for which we are uninformed. This cohort could have been an important contributor to understanding the phenomena being described.

The data base at the Hereditary Breast Cancer Clinic was not originally designed to be used for research. Due to the restrictions on personal health information in Manitoba, the only person who could access potential participants for the purpose of this study was the genetic counselor. Accrual was based on the sole interpretation of the inclusion and exclusion criteria by one person and could have included bias based on knowledge of the clientele.

The HBM was not the superlative mid-range theory for this study. A more complete use of the theory to include "cues-to-action", or the use of an additional theory to complement the HBM may have added depth of understanding to the study. Combining the HBM with a more in-depth qualitative component, such as personal interviews, may have enhanced the understanding of perceiving high risk and the screening practices of women with a family history of breast cancer.

Self-report of breast cancer screening may not be reliable information. However, with a retrospective study, medical records may not always be accessible, therefore self-report is acceptable and has been found to be reliable in previous research (King et al., 1990).

Finally, the use of a control group of women who have not attended genetic counseling may have offered insight into the retention of risk and screening information due to genetic counseling versus the media or family doctor. Women in this sample showed a discrepancy between stating they had not received screening recommendations and reporting the recommendations they had been given at the clinic. By seeing how well women from a control and a counseling group report risk and screening information, we might understand how much of the information is available to the general population, versus being retained through the clinic experience.

Recommendations for Future Research

The findings from this and other studies suggest that women with a family history of breast cancer overestimate their breast cancer risk, and that family history or perceived risk of breast cancer do not appear to have a significant impact on the utilization of mammography. The findings demonstrate a need for continued research, of adequate sample size, that attempts to reconcile the inconsistent results found among studies in this area.

In particular, there is a need for a more effective and consistent way to measure the concept of perceived risk. Investigators should endeavor to clarify the meaning of personal risk, which is important in fostering valid and consistent future research findings (Vernon, 1999). It would also be important to explore the cause of increased perceived risk. If family history has

less of an impact than previously assumed, healthcare professionals should target risk reduction efforts in another area (Lerman et al., 1994).

A major problem with a number of studies, including this one, is the lack of clearly stated theoretical frameworks. Only five of 25 articles reviewed made any reference to health behavior theory (Bastani et al., 1999; Hyman et al., 1994; Daly et al., 1996; Drossaert et al., 1996; Frost et al., 2000). Bastani et al., and Daly et al., briefly mentioned the Health Belief Model, without measuring all the constructs involved. Future studies using a sound theoretical framework with consistent measurement of all the constructs or concepts would be most helpful in promoting a clear understanding of the phenomena and concepts being explored and the interrelationships among concepts.

Future research needs to be more systematic in comparing women who are known to be at high risk with women of average risk on their risk perception and mammography behaviors. This will help determine if special education or counseling is needed for women at high risk of breast cancer. As more familial cancer clinics are offering genetic counseling, more women are becoming aware of their increased risk and subsequently being recommended for screening. It will be increasingly important for research, like that conducted by Schwartz, Rimer, et al. (1999), to determine the impact of counseling sessions in terms of whether women's perceived risk is reasonable and whether screening recommendations are adhered to. This type of research can help to justify the work that goes into counseling or can alert healthcare professionals to the need for increased communication with this patient group.

The relationship between personal risk estimates of breast cancer and depressive symptoms remains unclear, therefore more study is needed in this area. While this study found high levels of depressive symptoms among participants, other studies have not. Genetic counseling and discussions of family history of breast cancer may raise emotional issues that are not easily resolved. Research on interventions that identify and address these issues may be helpful for consultants to respond more consistently to the needs and concerns of this group.

Finally, a number of women in this study, under age 50, reported having mammograms. The evidence of benefit of mammography, especially for younger women is controversial. More research is needed to clarify the benefit of regular mammographic screening. As well, research to develop a decision guide in this area would assist women at higher-than-average risk by offering clear and consistent information on the value and possible results of mammography.

Task 3. Complete thesis report

Chapters one and two (Statement of the Problem and Literature Review) were drafted in the first three months of the project and finalized May 2004. Chapter three (Methodology) was drafted in months 4 to 6 and be finalized in May 2004. The remaining two chapters (Data Analysis and Discussion) were completed by mid June 2004. Copies of the completed thesis will be on file at the Elizabeth Dafoe Library, University of Manitoba and the National Library of Canada.

Task 4. Presentations

Abstracts were submitted throughout the year in preparation for dissemination of results. A presentation was made at the International Congress of Women's Health Issues in Victoria, British Columbia, June 2003 of the planned study (see appendix A); and posters were presented of the work in progress at the International Society of Preventive Oncology in Nice, France in February 2004 (see appendix B) and at the Canadian Nursing Research Conference in London,

Ontario in May 2004 (see appendix C). A presentation was prepared for thesis defense on August 12, 2004 and an article is being prepared for submission to Cancer Nursing.

Key Research Accomplishments

- There is conflicting evidence over the importance of accurate breast cancer risk perception.
- High levels of perceived risk were not associated with screening practices for women with a family history of breast cancer.
- There was no significant association between number of relatives with breast cancer and screening behaviors.
- Contradictory to other findings (Diefenbach, Miller, and Daly, 1999; Lerman et al., 1994; Meiser et al., 2000) who found older age to be positively associated with mammography use, no significant difference was found in mammography by age ($\chi^2 = 2.491$, $df = 1$, $p = 0.115$) or CBE by age ($\chi^2 = 0.003$, $df = 1$, $p = 0.995$).
- The findings showed a difference in mammography by education ($\chi^2 = 7.423$, $df = 1$, $p = 0.006$). Women with post-secondary qualifications were more likely to have a mammogram than those without.
- 34.6 percent of the sample scored above the cut-off of 16, suggesting high levels of depressive symptoms within the sample. Similarly, in a study of newly diagnosed for breast cancer by Beeber, Shea, and McCorkle (1998) the score on the CES-D was 15.69 (SD = 9.69) with 39.5 percent of participants scoring 16 or higher. This finding indicates that for those who attend genetic counseling, intervention is warranted for the high degree of depressive symptoms reported by the patients.

Reportable Outcomes

- Paper Presentation: International Congress on Women's Health Issues, Victoria, British Columbia, June 2003
- Poster Presentation: International Society for Preventive Oncology, Nice, France, February 2004
- Poster Presentation: Canadian Nursing Research Conference "Transforming Health Care Through Nursing Research" London, ON, May, 2004
- Brief report and copy of the thesis given to the Hereditary Breast Cancer Clinic so they can support the need for a follow-up surveillance clinic focused on psychosocial counseling.
- Manuscript submission to Cancer Nursing
- Master of Nursing degree
- Employment obtained as research coordinator for a three year multi-site, nationally funded project titled "Family Caregiver Coping in End-of-Life Cancer Care"

Conclusion

The results of this study suggest that perceived risk of breast cancer does not appear to have a significant impact on screening practices, however the small sample size needs to be taken into consideration when drawing conclusions based on these findings. More study is needed in this area to resolve the inconsistent findings among studies.

Improved methods of early detection of breast cancer are especially important for women with a strong family history because younger women may benefit from more effective screening methods.

While depression did not show a difference in perceived risk or screening practices, the high rate of depression among this sample is surprising and should be taken into consideration for any follow-up programs this clinic may plan in future. The psychological burden of breast cancer risk can be heavy and there is no reason for women in need of assistance to suffer.

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Appendix A

ABSTRACT

International Congress of Women's Health Issues

Title: Perception of Risk and Surveillance Practices For Women With A Family History of Breast Cancer
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With the advancement of genetic technology comes an increase in women with a family history of breast cancer seeking information about genetic testing and breast cancer risk. Women with a family history of breast cancer are encouraged to attend screening mammography at a younger age than average-risk women but there is limited data on the utilisation of cancer surveillance among high-risk women. The purpose of this study is to look at the relationship between risk perception and surveillance activities of women who have knowledge of having a hereditary connection to breast cancer. Thus, we will begin to understand how to approach this group of women during genetic counselling and recognise what may be interfering with surveillance activities. The study also highlights any difference in perceived risk, depression, and screening practices between women with one first-degree relative and women with more than one relative who have been diagnosed with breast cancer. With this information, we can identify a need for follow-up surveillance clinics, psychosocial counselling groups, and changes needed in the counselling approach or follow-up to best serve this population.

Appendix B

Perception of risk and surveillance practices for women with a family history of breast cancer

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Aim: The purpose of this study is to look at the relationship between risk perception and surveillance activities of women who have attended genetic counseling for familial breast cancer and to consider depression, education level, and age as predictors of compliance with breast cancer screening.

Methods: This is a retrospective, descriptive, correlation study using the Health Belief Model as a conceptual framework. A convenience sample of 100 women is being recruited from the Hereditary Breast Cancer Clinic at the Breast Health Centre, Winnipeg Regional Health Authority. Women are being surveyed to ascertain the impact of counseling on risk perception and screening practices.

Results: Data collection is expected to be completed in May 2004. The literature shows women overestimate their risk in spite of genetic counseling and that overestimation of risk does not result in participating in recommended screening behaviors. While family history of breast cancer is linked to a high perceived risk, it was not linked to screening behaviors. According to the literature, an inaccurate perception of risk of breast cancer does not appear to have a significant impact on the utilization of mammography.

Conclusions: Perceived risk of breast cancer is an abstract concept that is difficult to "quantitatively" capture on scaled tools. Therefore, care needs to be taken in understanding how the client is interpreting the information (e.g., probing for qualitative information). Increased understanding of the effect perceived risk and depression has on adherence to surveillance recommendations will assist clinicians with designing follow-up surveillance programs to reinforce accurate risk information and promote appropriate surveillance practices.

Martin, W. (2004, February). *Perception of risk and surveillance practices of women with a family history of breast cancer*. Poster session presented at the 7th International Symposium on Predictive Oncology, Nice, France.

Appendix C

PERCEPTION OF RISK AND SURVEILLANCE PRACTICES OF WOMEN
WITH A FAMILY HISTORY OF BREAST CANCER

Canadian Nursing Research Conference, London, Ontario

Introduction and study purpose

With the advancement of genetic technology comes an increase in women with a family history of breast cancer seeking information about genetic testing and breast cancer risk. Women with a family history of breast cancer are encouraged to attend screening mammography at a younger age than average-risk women but there is limited data on the utilization of cancer surveillance among high-risk women. The purpose of this study is to look at the relationship between risk perception and surveillance activities of women who have knowledge of having a hereditary connection to breast cancer.

Conceptual/theoretical framework

The Health Belief Model will be used as a framework.

Methods

Letters will be sent by the Winnipeg Breast Health Centre Hereditary Cancer Clinic's genetic counselor offering their past clients the opportunity to participate. Clients will be instructed to contact the principal investigator, and will then receive the questionnaires by mail with an addressed postage-paid return envelope.

Progress to date

Currently waiting for human subject approval from the granting body, data collection is expected to begin by January, 2004.

Potential implications for research, practice and/or policy

The findings will aid in understanding how to approach this group of women during genetic counseling and recognize what may be interfering with surveillance activities. With this information, we hope to identify a need for follow-up surveillance clinics, psychosocial counseling groups, and necessary changes in the counseling approach or follow-up to best serve this population.

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- Martin, W. (2004, May). *Perception of risk and surveillance practices of women with a family history of breast cancer*. Poster session presented at the Canadian Nursing Research Conference, London, Ontario.

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